

Association Between a Name Change from Palliative to Supportive Care and the Timing of Patient Referrals at a Comprehensive Cancer Center

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ABSTRACT

Purpose. Palliative care consultation services are now available in the majority of cancer centers, yet most referrals to palliative care occur late. We previously found that the term “palliative care” was perceived by oncology professionals as a barrier to early patient referral. We aimed to determine whether a service name change to supportive care was associated with earlier referrals.

Patients and Methods. Records of 4,701 consecutive patients with a first palliative care consultation before (January 2006 to August 2007) and after (January 2008 to August 2009) the name change were analyzed, including demographics and dates of first registration to hospital, advanced cancer diagnosis, palliative care consultation, and death. One-sample proportions tests, median tests, χ^2 tests, and log-rank tests were used to identify group differences.

Results. The median age was 59 years, 50% were male, and 90% had solid tumors. After the name

change, we found: (a) a 41% greater number of palliative care consultations (1,950 versus 2,751 patients; $p < .001$), mainly as a result of a rise in inpatient referrals (733 versus 1,451 patients; $p < .001$), and (b) in the outpatient setting, a shorter duration from hospital registration to palliative care consultation (median, 9.2 months versus 13.2 months; hazard ratio [HR], 0.85; $p < .001$) and from advanced cancer diagnosis to palliative care consultation (5.2 months versus 6.9 months; HR, 0.82; $p < .001$), and a longer overall survival duration from palliative care consultation (median 6.2 months versus 4.7 months; HR, 1.21; $p < .001$).

Conclusion. The name change to supportive care was associated with more inpatient referrals and earlier referrals in the outpatient setting. The outpatient setting facilitates earlier access to supportive/palliative care and should be established in more centers. *The Oncologist* 2011;16:105–111

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INTRODUCTION

The majority of cancer patients experience a number of distressful physical and psychosocial symptoms during the course of their illness that significantly affect their quality of life [1–6]. The goal of palliative care is to prevent and relieve suffering, and to improve the quality of life of patients and their families diagnosed with life-threatening or serious debilitating illnesses [7]. As defined by the World Health Organization, “palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications” [8]. A simultaneous care model with integration of palliative care services in early stages of the cancer patient’s illness trajectory has also been advocated by leading national organizations [9–13]. Over the years, the number of clinical palliative care programs in cancer centers, academic hospitals, and community hospitals all around the U.S. has increased dramatically [14–16]. One expectation of such hospital-based programs is that they can help integrate palliative care interventions earlier in the trajectory of illness [17]. However, referral of patients to palliative care have consistently been shown to occur late in the disease trajectory, and this represents one of the major barriers to improving palliative care access in the U.S. [16, 18–20].

Several studies have suggested that the term palliative care might be a deterrent to early referrals and that the term supportive care may be more favorable for some hospital-based palliative care programs [21–23]. In a recent survey of oncology clinicians at our institution [23], the overwhelming majority perceived the name palliative care to be a barrier to referral, and stated a greater likelihood of referring patients who were receiving active cancer therapies for primary or advanced cancer to a service named supportive care but no difference if patients were no longer receiving treatment for advanced cancer or were in transition to end-of-life care.

In order to improve the access of cancer patients who are in earlier stages of their illness, and based on the findings of our survey, we changed the name of our outpatient and inpatient consultation service from palliative care to supportive care in November 2007. This name change was accompanied by an institutionwide e-mail announcement from the Office of the Chief Medical Officer, as well as by our department, to all faculty, trainees, midlevel providers, and other employees. We did not attempt to provide any definition of the term supportive care as compared with palliative care, and did not state that the services provided by our team would change in any way as a result of the name change.

The main objective of this study was to determine whether the change in the service name would result in referral of cancer patients earlier in the illness trajectory, as defined by a longer interval from consultation to death, a shorter interval from advanced cancer diagnosis and registration to the hospital, and a higher percentage of patients with a nonadvanced cancer diagnosis.

PATIENTS AND METHODS

Study Design and Patient Eligibility

In this retrospective study, we reviewed our computerized database to identify all consecutive cancer patients who were seen for the first time in consultation by the palliative care team, either in the outpatient or inpatient setting in January 2006 to August 2007 (defined as the period before the name change) and in January 2008 to August 2009 (defined as the period after the name change). These dates were chosen to ensure that we assessed the same time frames for patients seen before and after the service name change from palliative to supportive care, which occurred on November 1, 2007. We excluded patients seen during the transition period of the name change, between September and December 2007. The palliative care program at The University of Texas M.D. Anderson Cancer Center (UTMDACC) consists of a group of full-time palliative care specialists who provide care in the inpatient and outpatient settings. We believed that a comparison between these two periods was feasible because the group composition and operation of our clinical palliative care program remained the same throughout the entire study period, other than the program name change. The UTMDACC institutional review board approved this study.

Data Collection

Information pertinent to patient demographics (age at first palliative care consult, gender, and ethnicity), date of registration (first contact of patient with institution), cancer diagnosis (location and stage), date of advanced cancer diagnosis at UTMDACC, date of first palliative care consultation, and date of death was evaluated. Patients were classified based on whether they were seen in the inpatient or outpatient setting. The date of death was obtained from a Social Security Death Index interactive search and hospital administrative records.

In this study, advanced cancer was defined as locally advanced, recurrent, or metastatic disease for solid tumors and relapsed or refractory disease for hematologic malignancies. Patients who were unable or unwilling to receive curative-intent therapies for any reason or referred for phase I treatment were also considered to have advanced cancer. In

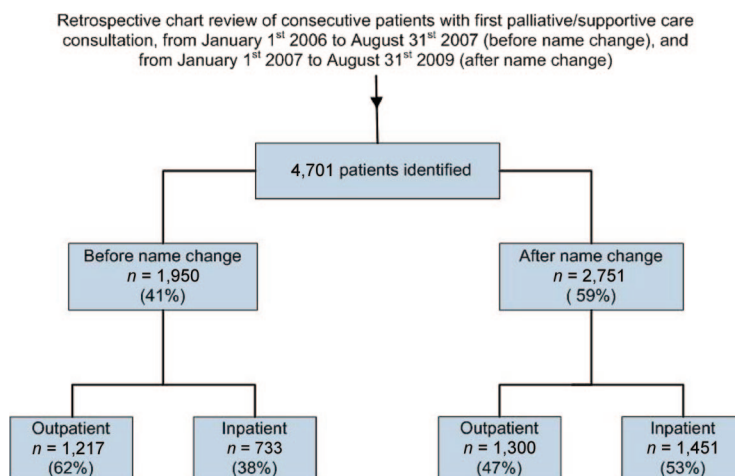


Figure 1. Number of new palliative care consultations before and after the name change from palliative care to supportive care in the outpatient and inpatient settings. *n* of patients = 4,701.

cases of patients with multiple malignancies, data were collected for the cancer most likely responsible for the patient's palliative care referral/death. We also obtained the number of new patient registrations at UTMDACC for the same time period from the hospital administration.

The data collection team consisted of the principal investigator (S.D.), who is a palliative care specialist, a palliative care specialty fellow, two research nurses, and the departmental data management team. The principal investigator reviewed >2,500 charts, trained all team members involved, and conducted independent chart review whenever any ambiguity arose. For the purpose of quality control, the principal investigator also randomly reviewed 300 additional charts.

Statistical Analysis

Descriptive statistics were used to summarize patient demographics, cancer diagnoses, and different time intervals. To determine the timing of patient access to palliative/supportive care, we examined three different time intervals: (a) from the date of hospital registration to the first palliative/supportive care consultation, (b) from the diagnosis of advanced cancer to the first palliative/supportive care consultation, and (c) from consultation to death or last follow-up. Time intervals were summarized with survival curves using the Kaplan–Meier method. Intervals of time for patients seen in the outpatient versus inpatient care setting, with solid tumors versus hematologic malignancies, and based on gender, race, and age were compared using two-sided log-rank tests of equality over strata. In addition, 95% confidence intervals were calculated for the median length of time. Time-to-event probabilities were estimated non-parametrically using Kaplan–Meier's product limit method (a). Cox proportional hazards regression models (b) were

used to model time-to-event as a function of the period before or after the name change. To examine survival, the time to death or censoring was computed in months since the first palliative care consult for each patient. Survival time was censored at the date of the last contact if death was not observed. Significance levels <0.05 were considered statistically significant.

RESULTS

In total, 4,701 patients had their first palliative/supportive care consultation during the defined period of the study. As shown in Figure 1, 1,217 (62%) patients were seen in the outpatient clinic and 733 (38%) patients were seen in the inpatient setting prior to the name change. After the name change, 1,300 (47%) and 1,451 (53%) patients were seen in the outpatient and inpatient settings, respectively. Patient demographics and tumor characteristics are summarized in Table 1. Overall, the majority of patients had solid malignancies and had advanced cancer.

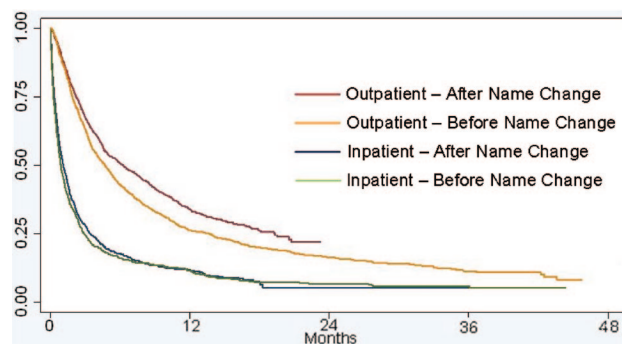
Timing of Referral to Palliative/Supportive Care Service

In the outpatient setting, the name change was associated with shorter time intervals to palliative/supportive care consultation, both from hospital registration (median, 9.2 months versus 13.2 months; hazard ratio [HR], 0.85; $p < .001$) and from advanced cancer diagnosis (5.2 months versus 6.9 months; HR, 0.82; $p < .001$). The time duration between consultation and death or last follow-up was correspondingly longer (6.2 months versus 4.7 months; HR, 1.21; $p < .001$) (Fig. 2). Importantly, we found that a higher percentage of patients who did not have an advanced cancer status (14%, versus 5%; $p < .001$) were referred to palliative/supportive care after the name change.

Table 1. Patient characteristics

Characteristic	All			Outpatient			Inpatient		
	Before	After	<i>p</i>	Before	After	<i>p</i>	Before	After	<i>p</i>
<i>n</i> of patients	1,950	2,751	<.001	1,217	1,300	.1	733	1,451	<.001
Median age, yrs (95% CI)	59 (59–60)	59 (58–60)	.14	60 (59–61)	59 (59–60)	.21	59 (57–60)	58 (58–59)	.89
Gender									
Female, <i>n</i> (%)	936 (48)	1,396 (51)	.07	596 (49)	631 (49)	.83	340 (46)	765 (53)	.005
Ethnicity, <i>n</i> (%)									
White	1,369 (70)	1,905 (69)	.9	889 (73)	943 (73)	.54	480 (66)	962 (66)	.76
Black	268 (14)	399 (15)		156 (13)	171 (13)		112 (15)	228 (16)	
Hispanic	208 (11)	291 (11)		118 (10)	114 (9)		90 (12)	177 (12)	
Other	105 (5)	156 (6)		54 (4)	72 (5)		51 (7)	84 (6)	
Primary cancer, <i>n</i> (%)									
Solid	1,782 (91)	2,483 (90)		1,159 (95)	1,247(96)		623 (85)	1,236 (85)	
Thoracic	364 (20)	482 (19)	.04	230 (20)	230 (18)	.13	134 (22)	252 (20)	.14
Head and neck	158 (9)	245 (10)		125 (11)	177 (14)		33 (5)	68 (6)	
Gastrointestinal	436 (24)	629 (25)		271 (23)	296 (24)		165 (26)	333 (27)	
Genitourinary	209 (12)	235 (9)		133 (11)	110 (9)		76 (12)	125 (10)	
Gynecological	161 (9)	256 (10)		100 (9)	113 (9)		61 (10)	143 (12)	
Breast	139 (8)	244 (10)		102 (9)	125 (10)		37 (6)	119 (10)	
Sarcoma	62 (3)	71 (3)		55 (5)	58 (5)		7 (1)	13 (1)	
Melanoma	41 (2)	52 (2)		32 (3)	34 (3)		9 (1)	18 (1)	
Other	212 (12)	269 (11)		111 (10)	104 (8)		101 (16)	165 (13)	
Hematological	168 (9)	268 (10)		58 (5)	53 (4)		110 (15)	215 (15)	
Advanced cancer status, <i>n</i> (%)									
Yes	1,872 (96)	2,493 (91)	<.001	1,155 (95)	1,119 (86)	<.001	717 (98)	1,374(95)	<.001
No	78 (4)	258 (9)		62 (5)	181(14)		16 (2)	77 (5)	

Abbreviation: CI, confidence interval.

**Figure 2.** Kaplan–Meier estimates for overall survival from first palliative care consultation. Comparison was conducted based on whether patients were first referred as outpatients or inpatients, and before or after the name change.

In the inpatient setting, the median time to first palliative/supportive care consultation was significantly longer after the name change, both from the date of hospital registration (4.5 months versus 2.4 months; HR, 1.9; $p < .001$)

and from the diagnosis of advanced cancer (2.8 months versus 1.7 months; HR, 1.47; $p < .001$). The overall time between referral and death/last follow-up did not differ significantly between the period before the name change and the period after the name change (0.9 months versus 1.1 months; HR, 0.97; $p = .2$) (Fig. 2). The percentage of patients without an advanced cancer status increased from 2% to 5% ($p < .001$).

Number of Referrals to Palliative/Supportive Care

After the name change, we observed a 41% greater number (2,751, versus 1,950 patients; $p < .001$) of new patients seen by our service, which was solely attributed to an increase in the inpatient setting (733 to 1,451 patients; $p < .001$). We did not detect any significant difference in the outpatient clinic (1,217 to 1,300 patients; $p = .098$). In an effort to control for spontaneous growth in hospital activity

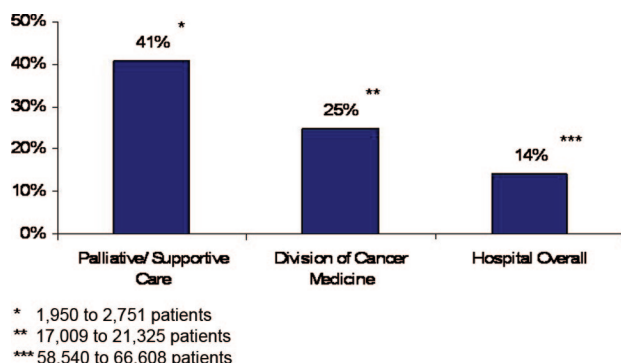


Figure 3. Percentage growth in new patient activity for palliative/supportive care, the Division of Cancer Medicine, and the hospital overall in the period after the name change compared with the period before the name change.

during the study period, we determined the proportion of new patients seen by palliative/supportive care compared with those seen overall by the Division of Cancer Medicine (DoCM), where our department is located. Palliative/supportive care consultations accounted for 11.5% of all DoCM consultations in the period before the name change and for 13% of all consultations in the period after the name change ($p < .0001$). The relative growth in the entire institution for the same time periods is also shown in Figure 3.

DISCUSSION

Integration of palliative care interventions into earlier stages of the cancer trajectory has been widely advocated [9–13], but unfortunately this has not been widely adopted in the U.S. In order to encourage referral of cancer patients at an earlier time to our service, we changed the name of the outpatient and inpatient consultation services from palliative care to supportive care. The objective of this study was to determine whether the name change resulted in earlier referral of cancer patients to our service.

Following the name change, in the outpatient setting, we observed that cancer patients were referred to palliative/supportive care earlier, as indicated by shorter time intervals to consultation from the day of hospital registration and from an advanced cancer diagnosis, and that a greater number of patients referred had potentially curable disease (14%, versus 5%). Further, after the name change, the median survival time (from time of consultation) was longer, by one and one half months. In contrast, in the inpatient setting, patients were not seen earlier in their illness trajectory. The median survival time of inpatients was about 1 month, and this did not differ between the periods before and after the name change. There was a relative increase in the number of female patients during the period after the name change, probably because of a relatively higher use of our program by the breast and gynecological programs (Table

1). Although these differences, per se, were not statistically significant, it is likely that, overall, they contributed to a slight increase in the number of female patients overall.

In the past two decades, although the number of hospital-based palliative care programs has dramatically increased all around the U.S., a majority of these programs offer only inpatient services [16]. As indicated by our study, relying exclusively on the inpatient setting as a referral base for palliative care is unlikely to result in early access to palliative care. Admission of cancer patients to acute care hospitals is usually a result of acute complications related to infections, thrombosis, bleeding, etc., and management vigorously undertaken by the oncology teams or general hospitalists. The palliative/supportive care team may be consulted to assist with uncontrolled symptoms, deteriorating medical status, complicated discharge issues, or hospice transition and end-of-life care. Given that the vast majority of such inpatients are in later stages of their disease, we did not expect a significant shift in the timing of referral for the inpatient setting. In the inpatient setting, our study did not find any significant difference in the time from consultation to death/last follow-up, but we are not able to interpret the meaning of the significant delay in the time to consultation from hospital registration and an advanced cancer diagnosis in the period after the name change. We suspect that this may simply reflect an overall increase in patients who were more severely ill.

In contrast, the outpatient center provides an opportunity to bring a host of palliative/supportive care services earlier to patients and their families. Because most oncology visits and treatments are delivered on an outpatient basis, an outpatient clinic is the ideal setting for integration. Through longitudinal follow-up, the palliative/supportive care team can build rapport with patients and their families; address their symptoms, distress, and health care needs in a timely fashion; and facilitate a gradual transition of care. Consistent with our hypothesis, we found that patients who were first seen as outpatients by the palliative care team were referred earlier after the name change to supportive care.

Following the name change, we also observed a significantly higher rate (41%) of new patient consultations overall, even after making adjustments for institutional growth. The increase was solely observed in the inpatient setting, because there was no significant change in the number of new patient consultations in the outpatient center. The dramatic increase in the number of inpatient referrals may have been related to the service name change, making it “less distressing” for the referrals to take place [21–24]. One likely explanation for the lack of increase in the outpatient setting is that, during the study time period, there was no change in

the number of clinic slots to accommodate a higher number of patient visits per day, and no increase in the number of palliative care physicians assigned to the clinic each day. With the exception of emergencies, appointments for new patient consultations are scheduled by administrative staff, based on clinic slot availability. Because of current space and team limitations, there is no system in place to see a larger volume of patients. However, it is expected that earlier referrals to the outpatient clinic will result in larger outpatient clinic activity. This can be addressed by either increasing the number of outpatient clinic slots available or increasing the interval between visits. In our center, the initial approach has been to increase the time between visits from an average of 2 weeks to 3 weeks. A third possible approach could be to decrease the length of visits, but this could deteriorate the quality of patient care. Finally, our program and others have started pilot programs of active telephone follow-up as a way of handling patient problems on a preventative basis and decreasing the outpatient clinic workload. More research is needed to better characterize the effectiveness of these different models for the management of the increasing workload brought on by the earlier referrals. In contrast, in the inpatient setting, all consults are called to a common pager and seen by palliative care fellows and faculty on a same-day basis, with a well-structured system with back-up faculty in place, allowing for flexibility in the number of patients seen by the team each day.

This study is consistent with findings from our survey of oncology clinicians who perceived the name palliative care to be a barrier to patient referral and that they would be more likely to refer patients earlier in the disease trajectory with a name change to supportive care [23]. Our findings strongly suggest that earlier integration of palliative care can occur only if the palliative care program has a major outpatient component. In this regard, it is concerning that a recent survey of cancer centers in the U.S. showed that <50% offer palliative care outpatient services [16].

This study has several limitations. First, data collection was done retrospectively. Because of the nature of our study question, we feel that the alternative design of a prospective cluster randomized controlled trial would not be feasible logistically and financially. Second, our study only showed a significant improvement in the number and timing of palliative care referrals after the name change, but it is not able to definitely establish a causal relationship. We tried to control for potential confounders such as institutional growth, but there may be other factors not accounted

for, such as changing characteristics, attitudes, and beliefs of referring physicians. Although a shift in patient demographics could also explain the change in the referral pattern, we did not detect any significant difference between the periods before and after the name change. Because of the nature of our institution as a comprehensive cancer center with a large patient volume, the results might not be generalizable to smaller cancer centers and oncology programs in other areas. However, the findings of our study regarding a higher overall number of referrals and earlier referrals in the outpatient setting confirm the findings of our previous survey study on the attitudes and beliefs of medical oncologists and midlevel providers regarding the term palliative care. We believe that these findings and the difference in referral pattern after the name change are not center specific but rather reflect perceptions among health care professionals in the U.S. regarding the strong associations among palliative care, hospice, and end of life. As a result of the aforementioned limitations, our findings should be considered preliminary until confirmed by other researchers.

In summary, we found that a name change from palliative care to supportive care was associated with a greater number of palliative care referrals in the inpatient setting and early referrals in the outpatient setting. Importantly, there was a rise in the proportion of cancer patients with early disease being referred to supportive care. These findings support our hypothesis that supportive care is a term more conducive to referral and facilitates integration between oncology and palliative care.

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